Purpose: To provide information to a new registered nurse at CCBD for gaining knowledge to provide care to patients and families seen through CCBD

Resources:

1. N drive: Gill folder: Nurse Coordinator-In Progress
2. National Hemophilia Foundation website
3. Attendance at Partners in Bleeding Disorders Education Program
   1. Basic – 2 day program
   2. PartnersPRN™ - online web based learning activities
   3. The Resource Room (http://www.rarecoagulationdisorders.org)
4. Children’s Hospital of Wisconsin
   1. IT – Epic training
5. Self-study modules
6. Protocol training documents: Gill file
7. Complete Epic training
8. Complete Velos training
9. Complete CHW orientation to MACC Fund Clinic
10. Sign and date section when completed

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| Topic |  | Content for discussion/Resource Materials | Date Completed/Initials |
| **People to Meet** | Social Workers | What is role?  Interaction with patients and families  Financial assistance  Insurance assistance |  |
|  | Pharmacy | Role  Product availability for home care  Programs to reduce medication cost |  |
|  | Physicians  Jen Massaro-Inpatient/Outpatient Coag/Thrombosis NP |  |  |
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| **Research** | Current research protocols |  |  |
|  | Research coordinators | How/when to contact |  |
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| **Bleeding Disorders** |  |  |  |
| **Hemophilia** |  |  |  |
|  | **Hemophilia A (Factor VIII deficiency)** |  |  |
|  | -Pathophysiology |  |  |
|  | -How inherited |  |  |
|  | -Diagnostic tests |  |  |
|  | -Coagulation studies |  |  |
|  | -Genetic testing |  |  |
|  | -Clotting factors |  |  |
|  | -Bleeding history |  |  |
|  | -Severity of disease |  |  |
|  | -Mild |  |  |
|  | -Moderate |  |  |
|  | -Severe |  |  |
|  | -Treatment |  |  |
|  | -Medications | Review medication dosing, side effects, administration |  |
|  | -recombinant Factor VIII concentrate |  |  |
|  | -DDAVP (Desmopressin acetate) |  |  |
|  | -Aminocaproic acid |  |  |
|  | -Prophylaxis regimen |  |  |
|  | -Acute bleeding |  |  |
|  | -Patient/family education |  |  |
|  | -Printed materials |  |  |
|  | -On-line resources |  |  |
|  | -CCBD resources |  |  |
|  | -Other services for patients/families |  |  |
|  | **Hemophilia B (Factor XI deficiency)** |  |  |
|  | -Pathophysiology |  |  |
|  | -How inherited |  |  |
|  | -Diagnostic tests |  |  |
|  | -Coagulation studies |  |  |
|  | -Genetic testing |  |  |
|  | -Clotting factors |  |  |
|  | -Bleeding history |  |  |
|  | -Severity of disease |  |  |
|  | -Mild |  |  |
|  | -Moderate |  |  |
|  | -Severe |  |  |
|  | -Treatment |  |  |
|  | -Medications |  |  |
|  | -recombinant Factor XI concentrate |  |  |
|  | -Aminocaproic acid |  |  |
|  | -Prophylaxis regimen |  |  |
|  | -Acute bleeding |  |  |
|  | -Patient/family education |  |  |
|  | -Printed materials |  |  |
|  | -On-line resources |  |  |
|  | -CCBD resources |  |  |
|  | -Other services for patients/families |  |  |
| **Von Willebrand Disease** | Types of Von Willebrand Disease |  |  |
|  | **Type I vWD** |  |  |
|  | **Type 2 vWD** |  |  |
|  | **Type 3 vWD** |  |  |
|  | **Acquired vWD** |  |  |
|  | Diagnosis |  |  |
|  | -Coagulation testing |  |  |
|  | -Platelet function test |  |  |
|  | -vWD antigen testing |  |  |
|  | -Bleeding history |  |  |
|  | -Treatment |  |  |
|  | -Medications | Review medication dosing, side effects, administration |  |
|  | -Recombinant vWF (Vonvendi® ) |  |  |
|  | -DDAVP (Desmopressin acetate) |  |  |
|  | -Aminocaproic acid |  |  |
|  | -Prophylaxis regimen |  |  |
|  | -Acute bleeding |  |  |
|  | -Patient/family education |  |  |
|  | -Printed materials |  |  |
|  | -On-line resources |  |  |
|  | -CCBD resources |  |  |
|  | -Other services for patients/families |  |  |
| **Other Factor Deficiency Diseases** | Factor I (Inherited fibrinogen deficiencies) |  |  |
|  | Factor II (Prothrombin deficiency) |  |  |
|  | Factor V |  |  |
|  | Factor VII (Proconvertin deficiency) |  |  |
|  | Factor X (Stuart-Prower factor deficiency) |  |  |
|  | Factor XI |  |  |
|  | Factor XII (Hageman factor) |  |  |
|  | Factor XIII (Fibrin stabilizing factor deficiency) |  |  |
| **Inhibitors** | Causes |  |  |
|  | Diagnosis |  |  |
|  | Treatment |  |  |
| **Bleeding Episodes** | Internal bleeding |  |  |
|  | -Joint Bleeds |  |  |
|  | -Bruising |  |  |
|  | -Intracranial Bleed |  |  |
|  | -Gastrointestinal bleeding (GIB) |  |  |
|  | External bleeding |  |  |
|  | -Nosebleeds |  |  |
|  | Scheduled Dental Procedures |  |  |
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| **Clotting Disorders** | Thrombosis | Meet with Bridgit to review |  |
|  | Review MCW protocols |  |  |
|  | Platelet Function Disorders |  |  |
|  | Plasminogen activator inhibitor (PAI-1) deficiency |  |  |
|  | Fibrinogen deficiencies (Congenital) |  |  |
|  |  |  |  |
|  | Medications | Review medication dosing, side effects, administration |  |
|  | -Warfarin (Coumadin) |  |  |
|  | -Antiplatelet medications |  |  |
|  | -Others |  |  |
|  |  |  |  |
|  | Treatment plans |  |  |
|  | Warfarin Management (adult and pediatric) |  |  |
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| **Clinic Visits** |  |  |  |
|  | Preparation for clinic visit |  |  |
|  | * Patient CCBD chart |  |  |
|  | * Patient Epic EHR |  |  |
|  | * Patient lab results |  |  |
|  | * Patient home infusion record |  |  |
|  | * Bleeding history form |  |  |
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|  | Schedule for clinic day |  |  |
|  | Post-visit Follow-up |  |  |
|  | * CCBD notes |  |  |
|  | * Epic notes |  |  |
|  | * Copy-Paste outlook to physicians |  |  |
|  | * Post visit letter to patient |  |  |
|  | * Note printed on label paper, reviewed and signed, then placed in CCBD patient file |  |  |
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|  | Monday Clinic |  |  |
|  | Tuesday Clinic |  |  |
|  | Thursday clinic |  |  |
|  | Menorrhagia Clinic (1st Friday of month) |  |  |
|  | Platelet Aggregation visit |  |  |
|  | Nurse Only visit |  |  |
|  | * DDAVP |  |  |
|  | * STIMATE |  |  |
|  |  |  |  |
| **Triage Calls** | How/where to record |  |  |
|  | RN note about reason for call |  |  |
|  | Physician driven protocol (work in progress) |  |  |
|  | * Protocol for Fever in patient with indwelling catheter or port |  |  |
|  | * Intracranial Bleed protocol |  |  |
|  | * General Surgery recommendations |  |  |
|  | * Joint Bleeds |  |  |
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| **Pediatric** |  |  |  |
|  | Pediatric Growth and Development | Can RNs attend CHW classes related to growth and development? Check with nursing education at CHW |  |
|  | Transition Program for 14-18 year olds (medical readiness) | Review with Dr. Malec |  |
|  | Meet with Angelica for training | Education for providers, schools about children with bleeding disorders |  |
|  |  | “Camp” |  |
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